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CHAPTER 7

EVALUATION OF PALLIATIVE CARE AT HOME: THE FAMILIES' PERSPECTIVE

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Submitted

Abstract

This study analyzes the delivery of palliative care at home in Romania. The research question is: how do families evaluate palliative care delivered by teams after the patient has died? The evaluation covers the following areas: communication; fulfillment of expectations; accessibility; conflicts; and overall satisfaction.

During the study period, 89 patients died while receiving palliative care at home. Overall satisfaction with the service was high among the family members. Relatives who were not the main caregiver showed less satisfaction. Most family members indicated that their expectations about palliative care had been fulfilled. The teams were always accessible to most relatives, but sometimes it was difficult for family members to get the right medicine or equipment. Half of those interviewed reported that conflicts in the family were prevented due to the delivery of palliative care.

It may be concluded that palliative care at home, delivered by specialist teams, is satisfactory in Romania from the perspective of the relatives of the patients involved.

Keywords: palliation, satisfaction, evaluation, family, palliative home care

7.1 Introduction

Palliative care facilities and services are not yet sufficiently available throughout Europe.¹ Both the cost of care in medical institutions and the patients' wish to die at home necessitate new care arrangements like palliative care services at home.^{2,3} This is especially important in Eastern European countries, which not only have a strong tradition of people wishing to die at home, but which also have a lack of health care resources. In Western Europe, a growing number of people die in nursing homes or hospices.⁴ This is less so in Central-Eastern European countries. In countries like Croatia, Hungary, Romania and Slovakia, nursing homes are largely absent and only a few hospice facilities exist.⁵

Several studies have shown that most terminally ill patients would prefer to spend their final days at home and that a great deal of care is already provided at home by GPs and nurses during this period.^{6,7} The quality of this palliative care at home has become an important issue. To assess this quality and to achieve efficient care provided by palliative care professionals, collaboration between family members of the patient and professional health care providers is very important.^{8,9,10} Therefore, it is extremely relevant to study the family members' perspective on palliative care.

Recent studies have shown that patients and their families are highly satisfied with their GPs and with palliative care services. However, most investigations into the families' satisfaction with palliative care have focused on the experiences of families whose relative was cared for as a patient in an institution.^{11,12,13} A telephone survey among family members whose relative had received palliative care at home showed that 92% of the respondents were satisfied with the home treatment and that 79% of the nurses and 82% of the physicians met the expectations of the family.¹⁴ A study by Teno and co-workers (2004) on families' experiences with relatives dying at home or with

hospice services showed the home situation to be favored.¹⁵ Families were satisfied and thankful for the palliative care delivery at home while care was being provided for the patients.^{16,17} However, this may change after the patient has died. Therefore, this article will describe the family members' opinion of their experiences of palliative care provision at home, as expressed some time after their relative has passed away.

This study describes the assessment of palliative care at home from the families' point of view after the death of the patient. The provision of information and communication are important aspects of palliative care. This is particularly the case in Romania, where openness about a terminal illness is not customary. The provision of information may therefore be a source of conflict. Since palliative care at home is a new phenomenon in Romania, it is important to know whether the expectations of the families were met. Health care is not easily accessible in Romania. For palliative care, it is essential that care professionals as well as the equipment and medication are available when needed.

The research question is: *How do families rate the care delivered by palliative care home teams after the patient has passed away?*

7.2 Methods

This study evaluates four palliative care teams, specially trained to deliver this type of care at home.

Between October 2002 and September 2004, the four teams provided palliative care at home for 106 patients with an illness, mainly cancer, in a terminal phase. During that period, 89 patients died. The family of the deceased patients was contacted by a social worker after the patient had died. Family members were asked to participate in an interview and to complete a questionnaire. On consent, a social worker, who was not involved in the

palliative care service process and who was thus independent from it, visited the family for the interview six to eight weeks after the patient had died.

Table 1 Number of patients and family members involved in the study

Team	Number of patients included in palliative care	Number of patients deceased	Number of respondents	Response percentage
Bucharest 1	20	15	12	80%
Bucharest 2	21	16	14	87%
Olt urban	37	36	28	78%
Olt rural	28	22	20	91%
TOTAL	106	89	74	83%

All (89) families were contacted. Seventy-four families (83%) participated in the study. Out of all interviewees, 51% (n=38) were the spouse who had been acting as the central informal caregiver, whereas 28% of the interviewees (n=21) were one of the patient's children who had been acting as the central informal caregiver, together with the patient's spouse. Nine interviewees were partner/child but were not the central caregiver and six interviewees proved to be other relatives who were not the central informal caregiver.

The reasons why some families (15 in total) did not participate in the study included:

- the family had left town or had left the country after the patient's death or the family could not be reached (4 cases);
- the family indicated that the period of care was very short and they were not able to answer the questions (4 cases);
- due to their suffering or mourning, the family did not want to keep in touch with the palliative care team or discuss the care process (2 cases);
- the family did not want to fill out the questionnaire and indicated that they did not have enough time because of their work commitments (2 cases);

- the family, after the first questions, refused to proceed because they did not understand the questions or the family indicated that it would not answer such questions, believing this kind of activity to be dangerous (2 cases);
- the family declared that it wanted another kind of help, e.g. material goods, and especially money, and would not answer the questions because it did not get the help it had hoped for (1 case).

Seventeen closed questions with pre-coded (two or four answer) categories and open questions giving the opportunity to explain or comment on the answer given measured the following aspects: the quality of information and communication; the families' expectations; accessibility of the palliative care service at home; conflicts caused by the palliative care; overall satisfaction with the delivered care.

The data was analyzed using a SPSS software package (SPSS Inc. Chicago, Ill). For categorical variables, chi square / phi testing for significance was used. For continuous variables, Pearson correlations were calculated. Statistical significance level was set at $p < 0.05$.

7.3 Results

Information and communication

The majority (69%) of the interviewed family members stated that they had received all the necessary information from the physician and nurse, that communication with the professionals had been very good and that all their questions had been answered. One quarter of the interviewed persons ($n=19$) believed they had not been fully informed. All but seven family members (9%) believed the patient had been very well informed. Only a few interviewed persons elaborated on the possible causes for the perceived lack of information. In all such cases the lack of information was related to the availability of medication.

Family members who did not have a central role as informal caregiver indicated more frequently that they had not received all the information they required from the professionals of the palliative care team.

Families' expectations

Eighty percent of the interviewed family members (n=59) stated that their expectations had been fully met by the physician and the nurse. However, this did not mean that everybody had received all they needed, although most patients had. When asked whether the patient had received all the medication and equipment he or she needed, ten family members (14%), who stated that all their expectations had been fully met, also indicated that they had not received all the necessary equipment and/or medication. However, of the 15 family members who indicated that not all expectations had been fully met, 13 had not received the necessary equipment and / or medication.

Family members who had not played a central role in the care process indicated more frequently that their expectations had not been fully met (ϕ .415; $p < .001$).

Accessibility

For both the patients and family members involved in palliative care, it was important that they could count on the help of the professionals when needed. Most family members (81%) stated they could reach the professionals immediately when needed. This was especially the case when the family member was the central informal caregiver.

Conflicts

The delivery of palliative care at home by the palliative care team seldom created any conflict within the family, according to the family members interviewed. Only two interviewed family members (2%) stated that the delivery of palliative care by the team caused minor conflicts. These cases were related to financial problems of the families, which were expected to be solved over time. More frequently, i.e. in 50% of all cases, it was reported that the care provided by the teams actually prevented conflicts in the family. The palliative care service at home relieved the pressure and stress on family members. It provided adequate information, which helped the family to cope with its problems. In particular, in those cases where children and the spouse were the central caregivers, the palliative care team at home prevented conflicts in the family (chi square 7.256 df 2; $p < 0.03$).

The prevention of conflicts was more prevalent in families seen by the teams in Bucharest compared to those seen in the Olt region (chi square 22.710, df 1; $p < 0.001$).

Overall satisfaction

All family members, when asked, indicated being (very) satisfied with the care delivered by the palliative care team at home. They were also asked how satisfied they believed the patient had been with the care and whether they would recommend the service to other families. Together, these three questions represent the overall satisfaction. The results show that 31 interviewed family members (46%) were very satisfied, 26 (38%) were satisfied and 11 family members (16%) were not satisfied. When dissatisfied, families indicated that they had expected more material support or money or that it had been difficult to obtain the medication needed. Satisfied family members stated that they did not realize so

much could be done to help the patient, e.g. in relieving discomfort, anxiety, pain and uncertainty. Families also said they had learned how to deal with the difficult situation at home (tension) and how to take care of the patient effectively. Others had felt supported by the regular visits of the nurse or the physician. Nearly all families commented positively on the teams and on the care they delivered. Overall satisfaction was related to the type of relationship the family member had with the patient (chi square 18.578; $p < 0.001$). These results show that families in which both partner and children took care of the terminally ill patient were either very satisfied or satisfied. Family members who were interviewed, but who were not the central caregiver, expressed more overall dissatisfaction.

As for the teams, significant differences concerning overall satisfaction existed between team 2 in Bucharest and the urban Olt team on the one hand and team 1 in Bucharest and the rural Olt team on the other. The former were less associated with overall satisfaction compared to the latter (chi square 31.657 df 3 $p < 0.001$).

Relationship between evaluation measures

Correlations between the five aspects evaluated were calculated to analyze how strong the association was between these aspects. The results presented in Overview 1 show that most aspects strongly correlate with each other.

Overview 1 Correlations between the indicators, evaluating palliative care at home from the families' perspective (bold = $p < .001$)				
	information	expectations	accessibility	conflicts
information	-			
expectations	.78	-		
accessibility	.74	.70	-	
conflicts	.03	.17	.14	-
overall satisfaction	.53	.60	.45	.37

The associations show that families who said they had been well informed and who had communicated well with the palliative care teams also felt their expectations had been fully met and help had been there when needed. Also, the fulfillment of expectations and experiencing good accessibility are significantly correlated.

Overall satisfaction is significantly associated with all the other aspects, i.e. if family members who were very satisfied with the delivered care stated that the information and communication with the team members had been (very) good, then the teams also had met all their expectations, had been very accessible and had prevented conflicts in the family. It is interesting to note that one aspect, i.e. 'preventing conflict in the family' is only significantly related to 'overall satisfaction'.

7.4 Discussion

Palliative care teams taking care of patients at home seem to have been successful from the perspective of the family members involved in Romania. This is in line with other research findings.^{12,14} In particular, family members who played a role as central caregiver were very satisfied with the information from and communication with the professionals concerned. Their expectations seem to have been largely met and they believed that the care team prevented conflicts. The service had been very accessible, in their opinion.

Sometimes, families expected more than just the delivery of palliative care. This often concerned the availability of medication and sometimes even the provision of money by the team. This was more often the case when the family members were not involved in the informal care process. Another problem was that the costs for several drugs were not covered by the health insurance. A typical difficulty in Romania is the availability and prescription of opioid analgesics. Obtaining such medication, if at all affordable by patients, requires a lot of paper work and, consequently, much of the time that they could have benefited the patient was lost.

The study with palliative care at home was set up in different regions, since infrastructure and facilities vary greatly between regions in Romania. These large differences did not result in differences in accessibility, as far as the family members were concerned. This surprising finding may be explained by the fact that people are used to the (in) accessibility of facilities and lack of infrastructure, especially in rural areas.

An interesting finding is that the palliative home care team may help prevent family conflicts. This aspect has not yet been explored in the international literature. The fact that this was more often the case in Bucharest may be explained by different attitudes in the metropolis, i.e. the reduced willingness to take care of family. When children were involved in the informal care giving, possible family conflicts were prevented by the palliative care service, highlighting the difficulties children experience when taking care of a dying parent. These difficulties may be due to time pressure and/or changing attitudes.

As reported, 15 families refrained from participation in the interview for various reasons. It should be kept in mind that these families might not have been very satisfied with the service delivered and were perhaps not willing to express such a reaction “in public”. Having, said that, their non-cooperation does not necessarily indicate dissatisfaction. In Romania, people are actually not accustomed to interviews, and many people consider it dangerous to express their opinion in public or to have their opinion recorded.¹⁸

The strong correlations between the aspects used to evaluate the palliative care at home from the families’ perspective indicate a strong coherence in the concept measures and in the answering patterns. This underlines the validity of the findings.

But it is clear that more research is needed into the palliative care process and the role of families, as has also been shown by other studies.^{19,20}

References

1. Baumgarten J, Making palliative care a priority topic of the European Health Agenda, Eurage, Graz, 2004.
2. Medigovich K, Porock D, Kristjanson LJ, Smith M. Predictors of family satisfaction with an Australian palliative home care service: A test of discrepancy theory, School of Nursing, Edith Cowan University, Churchlands, Western Australia
3. Hinton J, Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? St Christopher's Hospice, London, UK
4. Davies E, Higginson IJ (eds), The solid facts. Palliative Care, WHO, Copenhagen, 2004
5. Dumitrescu L, Olaroiu M, Bogdan C, Palliative care - between past and future [in Romanian], Revista Medicala Romana 2003; XLX(3):156-159
6. Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrave A, Terminal cancer care and patients' preference for place of death: A prospective study, BMJ 1990; 301:415-417
7. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Palliat Med 1994; 8:183-96
8. McWhinney IR, Bass MJ, Orr V, Factors associated with location of death (home or hospital) of patients referred to a palliative care team, CMAJ 1995; 152(3):361-7
9. Howarth G, Willison KB, Preventing crises in palliative care in the home. Role of family physicians and nurses. Can Fam Physician 1995; 4:439-45

10. Hinds C, The needs of families who care for patients with cancer at home: Are we meeting them?, *J Adv Nurs* 1985; 10:575-81
11. Morita T, Chihara S, Kashiwagi T, A scale to measure satisfaction of bereaved family receiving inpatient palliative care, *Palliat Med* 2002; 16(2):141-150(10)
12. Morita T, Chihara S, Kashiwagi T, Family satisfaction with inpatient palliative care in Japan, *Palliat Med* 2002; 16(3):185-193
13. Kreitzschitz K, Macpherson CC, End-of-life care. Perspectives from families and caregivers, Windward Islands Research and Education Foundation, St George's University School of Medicine, St George's, Grenada.
14. Arad H, Geva H, Rosin V, Kibrik R, Kersz I, Home palliative care of terminal cancer patients with family feedback: From the experience of the decision to continue the community care service in the North, Home Care Unit of Kupat Holim Haklalit, HaEmek Medical Center, Afula
15. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al, Family perspectives on end-of-life care at the last place of care, Center for Gerontology and Health Care Research, Brown Medical School, Providence, RI, USA
16. Kristjanson LJ, Indicators of quality of palliative care from a family perspective, *J Palliat Care* 1986; 1:8-17
17. Kristjanson LJ, Quality of terminal care: Salient indicators identified by families, *J Palliat Care*, 1989; 4:21-28
18. Bara C. The Romanian Health Care System in Transition from the Users' Perspective, PhD Thesis, University Groningen, 2003
19. Stajduhar KI, Examining the perspectives of family members involved in the delivery of palliative care at home, *J Palliat Care*, 2003; 19:27-35
20. Broback G, Bertero C, How next of kin experience palliative care of relatives at home, *Eur J Cancer Care*, 2003; 12:339-46